

## What is CFS?

ME/Chronic Fatigue Syndrome is a chronic, debilitating condition with as yet an unproven cause and unknown mechanism. Whilst there is no diagnostic test, a positive diagnosis can be made clinically, with a reasonable degree of certainty. CFS can affect every system of the body, and consequently, the range of symptoms is broad. People are affected to varying degrees of severity – some experience a mild form of the illness, whilst are so severely affected that they become housebound or bedridden.

## What symptoms are associated with CFS?

CFS is commonly characterised by profound physical and cognitive exhaustion, which is often delayed post-exertional in nature (appears 24 to 48 hours after the activity exposure and then lasts for more than 24 hours following exertion), and is not significantly alleviated by rest. Most sufferers will experience substantial impairment of short-term memory or concentration, in addition to flu-like symptoms such as pain or weakness in the joints and muscles, unrefreshing sleep, tender lymph nodes, sore throat and headache, and many will also experience a myriad of other symptoms (refer to Table 1).

Table 1: Selected Symptoms Experienced By CFS Patients <sup>†</sup>

Symptom Category	Example Symptoms <sup>‡</sup>
Fatigue	Post-exertional malaise (cognitive, physical/muscular)
Neuropsychiatric	General difficulty concentrating or thinking; difficulty in processing, learning & retaining new information, or notable short-term memory dysfunction; dyscalculia (inability to perform mathematical calculations); nominal aphasia (inability to recall names of objects and people); slurred or slowed speech; blurred vision; photophobia (heightened sensitivity to light); generalised headaches of a type different from previously; irritability or easily frustrated; personality changes & mood swings; depression, anxiety & panic attacks.
Neurologic	Unsteadiness when upright; dizziness generally, dizziness moving head or after standing; skin sensations or tingling sensations; paralysis.
Non-specific infectious or immunologic-like	Fever/Chills; sore throat; swollen neck or arm glands
Sleep Disturbance	Need to nap each day; difficulty falling asleep; difficulty staying asleep; awakening unrested
Respiratory	Earaches, tinnitus (ringing in ears); hyperacusis (heightened sensitivity to noise); sinus infections; shortness of breath
Musculo-skeletal	Myalgia (muscle aches and pains); muscle weakness; migratory joint aches and pains
Gastrointestinal	Irritable bowel, including diarrhoea, bloating, abdominal pain; anorexia; nausea
Intolerances	Alcohol intolerance; food intolerances; sensitivity to medications and other chemicals
Rheumatologic	Puffy face; jaw pain; dry eyes or mouth; morning stiffness; gelling
Cardiac/Vascular	Chest pain; tachycardia (palpitations) or rapid heartbeat at rest; orthostatic intolerance (low blood pressure when standing); poor circulation to extremities
Miscellaneous	Clinically unexplained weight changes; sensitivity to temperature changes, or hot/cold; impairments in body temperature control; abnormal sweating.

<sup>†</sup>These symptoms are not necessarily specific to CFS but are reported at a high rate by CFS patients; some are more commonly reported than others are; <sup>‡</sup>this is a non-exhaustive list.

Adapted from: CFIDS Association of America, 2001; MacIntyre, 1998; Komaroff et al, 1996.

Symptoms vary from person to person and may fluctuate (in severity, frequency, duration and type) from day to day, or even within a day. Energy levels are however typically lowest in the late afternoon (Jason et al 1995, cited by Michiels & Cluydts, 2001). The degree of debilitation experienced can range from impinging upon work or study commitments to rendering even the most basic of self-care tasks impossible, often necessitating full-time care. Functional impairment of people with CFS has been shown to be similar to, or greater than, that of people with other chronic disabling medical conditions (eg rheumatoid arthritis, untreated hyperthyroidism, myocardial infarction and sudden cardiac death survivors) and psychological conditions (eg major depression) (RACP, 1997; Kroenke et al, 1998, cited by Stevens, 2001).

### How is CFS diagnosed?

The internationally accepted, Centers for Disease Control and Research (CDC) research case definition [See box on right] sets out research participant inclusion criteria. Such criteria and protocol is similar but not exactly the same as the diagnostic process that a GP works through in order to classify someone as a 'ME/CFS Sufferer.'

As part of the diagnostic process, the GP will undertake a complete medical history, physical examination and minimal series of laboratory tests. The main purpose of such initial investigations is to detect other conditions that may be causing the fatigue and other symptoms. The history will usually include a discussion of circumstances leading up the symptom development.

The GP will also record a patient's symptoms, which may include remittent and acute-stage symptoms as well as current symptoms. Patients will tend to remember their prominent symptoms such as fatigue ("I'm tired all the time"); recalling the numerous other symptoms may be hindered by cognitive dysfunction. Hence, it is advisable for patients to make notes before the appointment, listing all the symptoms experienced, and any other important information (such as apparent initiating

#### CDC diagnostic criteria for CFS (Fukuda et al, 1994):

There must be:

1. Clinically evaluated, medically unexplained fatigue of at least six months' duration that is: of new onset, not a result of ongoing exertion, not substantially alleviated by rest, with a substantial reduction in previous levels of activity.
2. The occurrence of four or more of the following symptoms:
  - subjective memory impairment
  - tender lymph nodes
  - muscle pain
  - joint pain
  - headache
  - unrefreshing sleep
  - postexertional malaise (>24 hours)

#### Exclusion criteria

- Active, unresolved, or suspected other disease\* likely to cause fatigue
- Psychotic, melancholic or bipolar depression (but not uncomplicated major depression)
- Psychotic disorders
- Dementia
- Anorexia or bulimia nervosa
- Alcohol misuse or other substance misuse
- Severe obesity

or exacerbating factors), to ensure the GP has a complete detailed history of the illness.

Armed with a patient's history and having excluded other conditions through the appropriate tests, a GP can make a preliminary diagnosis quite early on. There is no fixed rule, but in accordance with the research definition, a doctor may choose to wait the full six months of illness duration before giving a patient the official diagnosis of 'ME/CFS.'

### What is the cause of CFS?

There is no one proven cause of CFS. However, up to 85% (60% – 85% depending on the study) of people with CFS experience a sudden-onset of the illness, directly after an infection, chemical exposure or traumatic life-event. Some have reported its onset after being vaccinated.

It is unlikely that a single cause is responsible for CFS. However, whatever the trigger(s) may be, the task of scientific research is to determine how the body is fundamentally affected by these triggers.

Research has shown many abnormalities in body function, but we are still a long way off putting the pieces together to find the 'central' problem. The following summaries are taken from the recently published UK CFS/ME guidelines (Jan 2002) to provide the reader with an idea of some of the 'theories of the illness.'

**"Immune** – Immunological abnormalities are common in patients with CFS/ME. The findings are mostly non-specific, and their relationship to the illness has not been established. The pattern suggests some immune dysregulation, with activation or suppression of different components, as indicated by changes in cytokine concentrations and cell surface markers. In atopic [allergic] patients, case reports suggest that allergic manifestations can be exacerbated or triggered.

**"Hypothalamic-pituitary-adrenal axis** – Several studies have found subtle neuroendocrine abnormalities, particularly hypoactivity of the hypothalamic-pituitary-adrenal axis. It is also possible that disturbances in hypothalamic function could contribute to some CFS/ME symptoms such as fatigue, sleep problems, and disturbed thermoregulation. The possibility remains that these changes are directly or indirectly involved in pathogenesis.

**"Central nervous system** – Many of the symptoms of CFS/ME suggest dysfunction of the central nervous system. These could include cognitive disturbance, central fatigue (e.g. when movement requires increased mental effort), and disrupted neural regulatory mechanisms (e.g. those involved in sleep and temperature regulation). These changes could be primary or secondary to some widespread process.

"One suggested primary change in the central nervous system of patients with CFS/ME is abnormal brain blood flow, particularly involving the brain stem.

"However, many of these findings are inconsistent. Furthermore, regional brain blood flow can be altered by factors unrelated to any disease process; it is also subject to autoregulation, which means that local changes in blood flow could reflect altered activity in that brain region rather than the cause of altered activity.

"Measurement techniques are still being developed and selection of controls with other brain disorders is crucial to interpretation of the subtle changes seen. Magnetic resonance imaging studies have found subtle white matter abnormalities in some individuals, more common in those without coexistent psychiatric conditions, leading to the hypothesis that some CFS/ME patients have a subtle encephalopathy. The numerous studies on cognitive functioning have not always found consistent results and can be criticised for not reflecting the severity of subjective complaints. However, it seems likely that cognitive dysfunction in CFS/ME cannot be explained solely by the presence of a coexistent psychiatric disorder. Vestibular dysfunction is proposed to explain the widely reported symptom of "dysequilibrium".

**"Peripheral lesions** – The roles of dysfunction in the peripheral nervous system and muscles are uncertain, though some indirect evidence and specific symptoms in individuals have implicated them.

**"Autonomic nervous system** – Autonomic dysfunction seems to play a part but its role is not established. There is inconsistent evidence as to whether autonomic abnormalities, in particular neurally mediated hypotension, are part of a primary disease process or due mainly to inactivity associated with CFS/ME. For example, one study has found evidence of lower cardiac stroke volumes – a finding that may indicate covert cardiac dysfunction or reduced blood volume. It should also be noted that low fluid and salt intake with or without increased loss may be important in causing orthostatic problems in some patients."

It is important that we differentiate between causative agents/triggers and opportunistic ones. Many people over the years have made claims about what causes CFS. Just because someone finds something unwanted in our systems, it does not mean that it is causing the CFS. It may simply

be taking advantage of a person with ME/CFS's lack of ability to fight it.

### **How common is CFS?**

Whilst prolonged and disabling fatigue is present in 10-25% of patients presenting to general practitioners (RACP, 1997), CFS is far less common, with current estimates of approximately 200-700 CFS cases per 100 000. This equates to about 36 000 -- 126 000 Australians having the illness, which is comparable to the prevalence of various auto-immune diseases, such as multiple sclerosis (RACP, 1997).

### **Who is most likely to have the illness?**

All race, age and socio-economic status groups are at risk for CFS (RACP, 1997). There is now consistent evidence that what was once dubbed the "Yuppie Flu" may actually be more common in people from more socially disadvantaged groups (Jason et al, 1999; RACP, 1997). The illness additionally appears to be more common in women, and predominantly affects young adults (with a peak age of onset between 20 and 40 years). However, children and adolescents can also develop the illness; up to 20% of previous diagnoses have been reported in the age group of 10-19 years of age (Jason et al, 1999; Lloyd et al, 1990).

### **What is the cost of illness to the individual?**

The economic burden to the individual is substantial, with CFS sufferers at risk of being unemployed, receiving disability income, or working part-time (Jason et al, 1999). These financial constraints add to the emotional burden attributed through losing one's independence (reduced capacity to take care of oneself in every aspect, from financial to personal care needs), identity (through reduced work capacity and achievement), and capacity to pursue pleasurable leisure activities.

### **Do patients recover?**

The course of CFS varies widely. Some patients find they can resume work and other activities, though they may still continue to experience symptoms and never regain previous levels of productivity. Many report partial remissions with subsequent exacerbations (or flare-ups).

Studies have shown that only 6-10% of adult ME/CFS sufferers, who have been symptomatic for about five years, experience a full-recovery (Wilson et al, 1994; Joyce et al, 1997). It must be noted that the patients in these studies may not be representative of the entire CFS patient population, and such figures should not be considered as individually prescriptive. Certainly some patients recover long before the 5-year duration of illness. However, there is no disputing that some patients do experience life-long severe incapacitation and are often neglected in terms of appropriate health and community care and acknowledgment by researchers of the illness. The outlook for children is predicated to be significantly better than that for adults, with 54-94% of research subjects reporting recovery over the periods of follow-up (Joyce et al, 1997).

### **Which therapies assist recovery?**

Various drug treatments (antiviral, immunoregulatory, metabolic, supplemental nutritional and antidepressive) have been subjected to rigorous research but none has demonstrated definite clinical benefit (RACP, 1997; Reid et al, 2000; Whiting et al, 2001).

At the present time, *therapy* is based upon the alleviating or minimising presenting symptoms.

Common medical approaches include medications for pain, sleep disturbances, digestive problems, depression/anxiety, flu-like symptoms and orthostatic intolerance, amongst others. Additional supportive treatments such as cognitive behavioural therapy, changes in diet, exercise

modifications, and sleep/rest management may also prove to be of benefit.

## **An Illness with Many Names**

Somewhat potentially confusing, is the large number of names that have been utilised in an attempt to describe this illness:

ME, or **Myalgic Encephalomyelitis**, was first used in 1956 to describe the condition. The name suggests muscle pain and inflammation of the brain - originally thought to be the cause of the illness.

In the UK and other parts of the world the term ME is still used although some groups have moved to the term **Myalgic Encephalopathy** which suggests muscle pain and brain dysfunction. This is a far more accurate reflection of the condition, but in no means a complete description of it.

In 1988 the term **Chronic Fatigue Syndrome** was coined by some research groups in the USA. This name 'took off' in some parts of the world and has been used in clinical settings as well as research ones.

Interestingly in the USA, the name CFIDS or **Chronic Fatigue Immune Deficiency Syndrome**, was adopted as the clinical term for the condition, based on new theories at the time of the underlying cause of the illness. This is also not considered an accurate description of the disease, but no alternative has yet been found and so it is still used in the USA.

Another common name is **Post Viral Syndrome** or PVS; this accurately describes those people whose 'ME/CFS' has commenced directly after a viral infection.

ME and CFIDS inappropriately imply that the cause of the illness has already been delineated. Regardless, many patients and researchers favour these names in comparison with the trivialising alternative of CFS, and there has been a push to pen a new, more suitable name. However, Fukuda et al, (1994) explain: "... *changing the name without adequate scientific justification will lead to*

*confusion and will substantially undermine the progress that has been made in focusing public clinical and research attention on this illness. We support changing the name when more is known about the underlying pathophysiological process or processes associated with the CFS...."*

Until the cause and mechanism of the illness are known, any attempt to name it with a name that implies what it is will be contentious.

## **Rest/Activity**

It is important for people with CFS to remain as active as possible, by avoiding unnecessary bed rest during the day. However, the level of activity and bed rest will depend on the severity of the condition. For those at the more severe end of the scale, activity might be having a shower, or walking to the toilet. The patient may not be able to do more than some basic stretching to maintain body flexibility.

It is likewise very important for sufferers of CFS avoid over-activity. Genuine CFS sufferers will not get better, or gain anything, by pushing themselves harder in attempting to accomplish the tasks or activities that they once performed with ease. Pushing too hard, especially in the early stages may be quite harmful, or at least inevitably exacerbate the condition.

Living with CFS is hence often a matter of getting the activity balance right – avoiding excessive activity and overdoing things, but also maintaining as much activity as possible, such that excessive deconditioning does not occur. It is however, up to the patient to personally determine that level.

## **Supportive Counselling**

Having to endure the symptoms of CFS is difficult enough but its devastating physical effects can additionally have significant emotional implications. Relationships may be adversely affected and a sufferer may be frequently left feeling understandably frustrated and despondent. Living with a chronic illness is tough. If a person with CFS

is finding it difficult to cope with the grind of being tired and fatigued all the time, the frustration of unachievable goals, then a psychologist consultation may be of benefit.

Such a consult does not imply that a patient's illness is all in his or her head. However, a good practitioner can help a patient sort through feelings, thoughts and responses to their illness, hence helping to reduce the emotional burden of the illness.

### **Cognitive Behaviour Therapy (CBT)**

Cognitive behaviour therapy may be useful in some cases (a small percentage) of people with CFS. Sometime people with chronic illness get into negative, irrational thought patterns that become entrenched. This can exacerbate poor health. There is no shame in consulting a psychiatrist to deal with such issues. (We reject a lot of the hype surrounding CBT – supportive counselling is more than adequate for most people who are not coping with their ill health. It is important that we affirm that most people with CFS cope very well, do not need counselling, and are truly inspirational people.)

### **How can I stay in touch with the latest ME/CFS research findings?**

Sufferers of CFS (and interested others) can be alerted to research trials requesting participants, and research findings thereof, by becoming a member of their local or state ME/CFS Society, such as The ME/ CFS Society of SA Inc.

Scientific research methodology and technology is being continuously refined and improved upon; sufferers should remain hopeful that further research will more clearly delineate the physiological basis of the illness, and hence facilitate the trial of potentially beneficial treatments.

Currently, Australian research is being actively pursued by groups in Adelaide (representing The

University of Adelaide, The Royal Adelaide hospital and The Queen Elizabeth Hospital) and a group in Newcastle (University of Newcastle). Whilst still in its 'early days' such research efforts are helping to advance the worldwide quest for knowledge regarding this illness.

The ME/CFS Society (SA) is commencing a patient register that anyone can sign up to which will keep them (member or non-member) informed about up-coming research projects in SA. This collaboration, between the Society, researchers and willing persons with CFS, is intended to assist SA become a Research centre of excellence for CFS.

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